



## MEMORANDUM

To: Subcommittee on Health Members and Staff  
From: Committee on Energy and Commerce Majority Staff  
Re: Health Subcommittee Hearing on February 14, 2024

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The Subcommittee on Health will hold a hearing on Wednesday, February 14, 2024, at 10:00 a.m. (ET) in 2123 Rayburn House Office Building. The hearing is entitled “Legislative Proposals to Support Patients and Caregivers.”

### I. Witnesses

- **Dr. Andy Shih, PhD**, Chief Science Officer, Autism Speaks
- **Mr. Corey Feist, JD, MBA**, Co-Founder and CEO, Dr. Lorna Breen Heroes’ Foundation
- **Dr. Joanne Pike, DrPH**, President and CEO, Alzheimer’s Association
- **Dr. Gordon Tomaselli, MD**, Former President, American Heart Association; Marilyn and Stanley M. Katz Dean, Emeritus and Professor of Medicine, Albert Einstein College of Medicine; Adjunct Professor of Medicine, Johns Hopkins University School of Medicine
- **Ms. Michelle Whitten**, President, CEO, and Co-Founder, Global Down Syndrome Foundation
- **Mr. Randy Strozyk**, President, American Ambulance Association
- **Dr. Christina Annunziata, MD, PhD**, Senior Vice President of Extramural Discovery Science, American Cancer Society

### II. Background

As the nation’s public health needs continue to evolve, an examination of existing programs is necessary to understand the current landscape and identify any gaps that may need to be addressed. This hearing will explore several bills addressing various areas of public health, including resources for emergency medical services and health care providers, maternal and pediatric health, disease research and prevention, support for family caregivers, and increased access to care.

#### Emergency Medical Services (EMS) & Health Care Provider Resources

Rural EMS and fire agencies experience unique challenges while serving patients – they are often the only health care provider in certain areas and may face difficulty in recruiting and retaining workers. The Rural Emergency Medical Services Training program was originally authorized through the Agriculture Improvement Act of 2018 and

provides support to recruit and train EMS personnel in rural areas with a focus on addressing substance use disorders (SUD) and co-occurring disorders.<sup>12</sup>

Treating infants and children seeking emergency medical care requires specialized skills, training, and equipment. A recent study found that if all emergency departments that participated in the study had been well-prepared for pediatric patients, more than 1,400 deaths may have been prevented during the study years.<sup>3</sup> The Emergency Medical Services for Children (EMSC) program helps to expand and improve emergency care, or “pediatric readiness,” for children.

Physician burnout and mental health conditions continue to grow at alarming rates, a recent review from 2023 states that about half of practicing physicians reported burnout.<sup>4</sup> The Dr. Lorna Breen Health Care Provider Protection Act was originally signed into law in 2022, which authorized resources to health care entities to help improve mental health training and awareness for health care professionals.

Individuals who have experienced human trafficking oftentimes encounter a health care or social service provider at some point during or after their exploitation. The Stop, Observe, Ask, and Respond (SOAR) to Health and Wellness Act was originally signed into law in 2018 and authorizes resources to help build capacity in local communities to identify and respond to the various needs of individuals who have experienced trafficking.<sup>5</sup>

### Patient Research & Prevention

The programs reauthorized under the **Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2024, Congenital Heart Futures Reauthorization Act of 2024, Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act of 2024, NAPA Reauthorization Act, Alzheimer's Accountability and Investment Act, and SCREENS for Cancer Act of 2023**, and the initiatives under **SHINE for Autumn Act of 2023, Women and Lung Cancer Research and Preventive Services Act of 2023, Cardiomyopathy Health Education, Awareness, Research, and Training in the Schools (HEARTS) Act of 2023, and DeOndra Dixon INCLUDE Project Act of 2024** will support and build upon efforts to facilitate additional and continued research, services, education and awareness, training, and best practices related to identification, prevention, and treatment of each respective disease and/or related condition.

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<sup>1</sup> Public Law 115-334: Agriculture Improvement Act of 2018: <https://www.govinfo.gov/app/details/PLAW-115publ334>

<sup>2</sup> Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, FY2024 Rural Emergency Medical Services Training: <https://www.samhsa.gov/sites/default/files/grants/pdf/fy-2024-ems-training-nofo.pdf>

<sup>3</sup> Emergency Department Pediatric Readiness and Short-term and Long-term Mortality Among Children Receiving Emergency Care: <https://pubmed.ncbi.nlm.nih.gov/36637819/>

<sup>4</sup> 5 things health care organizations learned about burnout this year: <https://www.ama-assn.org/practice-management/physician-health/5-things-health-care-organizations-learned-about-burnout-year>

<sup>5</sup> Public Law 115-398 – Stop , Observe, Ask, and Respond to Health and Wellness Act of 2018

- **Autism** affects an estimated 1 in 36 children in the United States.<sup>6</sup> Signs of autism usually appear by age 2 or 3, but can appear even earlier, sometimes as early as 18 months. Research shows that early intervention leads to positive outcomes later in life for people with autism.<sup>7</sup>
- About 40,000 babies are born with a **heart defect** each year in the United States, or about 1 percent of births. As medical care and treatment have advanced, people with heart defects are living longer and healthier lives; currently, it is estimated that more than 2 million people in the United States are living with a heart defect.<sup>8</sup>
- An estimated 6.7 million Americans aged 65 and older are living with **Alzheimer's** in 2023. By 2050, this number is projected to rise to 12.7 million. About 1 in 9 people aged 65 and older (10.7 percent) has Alzheimer's, and 1 in 3 seniors dies with Alzheimer's or another dementia.<sup>9</sup>
- For women aged 50 to 74 years old, **breast cancer screening** every 2 years reduces breast cancer deaths by 26 percent, or 7 deaths averted for every 1,000 women screened. When diagnosed at the earliest stage, almost 98 percent of women diagnosed with breast cancer live for 5 years or more, compared to about 31 percent of those diagnosed at the most advanced stage.<sup>10</sup>
- **Stillbirth** affects about 1 in 175 births, and each year about 21,000 babies are stillborn in the United States.<sup>11</sup> Worldwide, there are more than 2.6 million stillbirths every year.<sup>12</sup> While there have been incredible advances and improvements in medical technology over the last 30 years, including in prenatal care, the rate of early stillbirth has remained about the same.<sup>13</sup>
- **Lung cancer** is the third most common cancer in the United States.<sup>14</sup> About 10 to 20 percent of lung cancers happen in people who never smoked or smoked fewer than 100 cigarettes in their lifetime.<sup>15</sup> Worldwide, over 600,000 women die of lung cancer each year.<sup>16</sup>
- In the United States, more than 30,000 children in the U.S. are diagnosed with some form of **cardiomyopathy**.<sup>17</sup> Generally, the immediate use of an automated external defibrillator (AED) or CPR can double or triple the person's chance of survival.<sup>18</sup>

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<sup>6</sup> <https://www.cdc.gov/mmwr/volumes/72/ss/ss7202a1.htm>

<sup>7</sup> <https://www.autismspeaks.org/what-autism>

<sup>8</sup> <https://www.cdc.gov/ncbddd/heartdefects/materials/5-things-to-know.html>

<sup>9</sup> <https://www.alz.org/alzheimers-dementia/facts-figures>

<sup>10</sup> <https://www.cdc.gov/chronicdisease/programs-impact/pop/breast-cancer.htm>

<sup>11</sup> <https://www.cdc.gov/ncbddd/stillbirth/facts.html>

<sup>12</sup> <https://starlegacyfoundation.org/about-stillbirth/>

<sup>13</sup> <https://www.cdc.gov/ncbddd/stillbirth/facts.html>

<sup>14</sup> <https://www.cdc.gov/cancer/lung/statistics/index.htm>

<sup>15</sup> <https://www.cdc.gov/cancer/lung/nonsmokers/index.htm>

<sup>16</sup> <https://www.lungcancerresearchfoundation.org/for-patients/women-and-lc/>

<sup>17</sup> <https://www.childrenscardiomyopathy.org/pages/about-disease/vital-facts/>

<sup>18</sup> <https://www.heart.org/-/media/files/health-topics/answers-by-heart/what-is-an-aed.pdf>

- **Down syndrome** is the most common chromosomal condition diagnosed in the United States. Each year, about 6,000 babies born in the United States have Down syndrome, affecting about 1 in every 700 babies.<sup>19</sup>

### Support for Family Caregivers

Family caregivers provide informal support to family members across all age groups, disabilities, and chronic conditions. The Lifespan Respite Care Program was enacted by Congress in 2006 and last reauthorized in 2020.<sup>20</sup> The program provides resources to states to provide and improve community-based respite care services to provide temporary relief to family caregivers and to support workforce development by enhancing training and recruitment activities.<sup>21</sup>

### Access to Care

Recent data suggests that over 1.5 million Traumatic Brain Injuries (TBI) are sustained each year.<sup>22</sup> TBI's usually happen when an outside force causes severe damage to the brain, this can impact a person's life in many ways and patients often require a multidisciplinary team that offer a range of wraparound services.<sup>23</sup> The TBI Act was originally signed into law in 1996 and provides resources to states to help support individuals diagnosed and living with a TBI.

There are fifty-five poison centers nationwide that help with poison emergencies, provide assistance to health care professionals, and disseminate poison prevention treatment education to the public.<sup>24</sup> The Poison Control Center Enhancement and Awareness Act was originally signed into law in 2000 and established a nationwide toll-free number, a media campaign, and authorized resources to regional poison control centers to ensure they can continue operating.<sup>25</sup>

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<sup>19</sup> <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome.html>

<sup>20</sup> Public Law 109-442: Lifespan Respite Care Act of 2006: <https://www.govinfo.gov/app/details/PLAW-109publ442>

<sup>21</sup> Administration for Community Living: Lifespan Respite Care Program: <https://acl.gov/programs/support-caregivers/lifespan-respite-care-program>

<sup>22</sup> Mayo Clinic, Traumatic Brain Injury Model Systems National Database: <https://www.mayo.edu/research/centers-programs/traumatic-brain-injury-model-system/projects/nidilrr-tbi-national-database>

<sup>23</sup> Administration of Community Living, Traumatic Brain Injury (TBI): <https://acl.gov/programs/post-injury-support/traumatic-brain-injury-tbi>

<sup>24</sup> Health Resources & Services Administration, Poison Centers: <https://poisonhelp.hrsa.gov/poison-centers>

<sup>25</sup> Public Law 106-174: Poison Control Center Enhancement and Awareness Act: <https://www.govinfo.gov/content/pkg/PLAW-106publ174/pdf/PLAW-106publ174.pdf>

### **III. Legislation**

#### **H.R. 6160, To amend the Public Health Service Act to reauthorize a lifespan respite care program (Reps. Molinaro and Cárdenas)**

This legislation reauthorizes the lifespan respite care program through fiscal year 2028.

#### **H.R. 7208, To reauthorize the Traumatic Brain Injury program (Reps. Pascrell and Bacon)**

This legislation reauthorizes certain programs with respect to Traumatic Brain Injuries (TBI). The programs reauthorized in this legislation may allocate resources for TBI prevention, improving access to TBI rehabilitation, and TBI patient advocacy systems.

#### **H.R. 7251, To amend the Public Health Service Act to reauthorize certain poison control programs (Reps. Chavez-DeRemer, D. Joyce, Davis, and Cherfilus-McCormick)**

This legislation reauthorizes certain poison control programs. These programs include the maintenance of the national toll-free phone number, the promotion of poison control center utilization, and the maintenance of a program that awards grants to accredited poison control centers.

#### **H.R. 7153, To reauthorize the Dr. Lorna Breen Health Care Provider Protection Act, and for other purposes (Reps. Wild and Kiggans)**

This legislation reauthorizes the Dr. Lorna Breen Health Care Provider Protection Act, which directs the Secretary of Health and Human Services (HHS) to allocate resources to health care entities for programs that promote the utilization of mental health and substance use disorder services among health care professionals.

#### **H.R. 6960, Emergency Medical Services for Children Reauthorization Act of 2024 (Reps. Carter and Castor)**

This legislation reauthorizes the Emergency Medical Services for Children program for fiscal years 2024 through 2029.

#### **H.R. 4646, SIREN Reauthorization Act (Reps. D. Joyce and Dingell)**

This legislation reauthorizes and modifies the rural emergency medical services (EMS) training and equipment assistance program for fiscal years 2024 through 2028.

**H.R. 7213, Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act of 2024 (Reps. C. Smith and Cueller)**

This legislation reauthorizes certain programs related to autism spectrum disorder, including the Developmental Disabilities Surveillance and Research Program; Autism education, early detection, and intervention; and the Interagency Autism Coordination Committee at currently appropriated levels for fiscal years 2025 through 2029.

**H.R. 7189, Congenital Heart Futures Reauthorization Act of 2024 (Reps. Bilirakis, Soto, Carter, Schiff, Salazar, and Cárdenas)**

This legislation reauthorizes a national congenital heart disease research, surveillance, and awareness program through fiscal year 2029.

**H.R. 7218, Building Our Largest Dementia (BOLD) Infrastructure for Alzheimer's Act of 2024 (Reps. Guthrie, Tonko, C. Smith, and Waters)**

This legislation reauthorizes programs to support states, local public health departments, and other entities in their efforts to educate, support early detection and diagnosis, reduce associated risks, support patients and caregivers, and promote public health knowledge and awareness of Alzheimer's disease and related dementias, among other activities, at currently appropriated levels for fiscal years 2025 through 2029.

**H.R. 2706, Charlotte Woodward Organ Transplant Discrimination Prevention Act (Reps. Cammack and Dingell)**

This legislation prohibits health care providers and other entities from denying or restricting an individual's access to organ transplants solely on the basis of the individual's disability, except in limited circumstances.

**H.R. 620, Alzheimer's Accountability and Investment Act (Reps. C. Smith, Tonko, and Waters)**

This legislation requires the National Institutes of Health (NIH) to continue to submit an annual budget estimate to Congress to achieve the initiatives and goals included in the National Plan to Address Alzheimer's Disease.

**H.R. 619, NAPA Reauthorization Act (Reps. Tonko, C. Smith, and Waters)**

This legislation reauthorizes the National Alzheimer's Project through 2035 and makes certain modifications to the Project, including updating the Project's purpose and revising the Advisory Council on Alzheimer's Research, Care and Services by expanding the membership and its reporting requirements.

**H.R. 6829, Cardiomyopathy Health Education, Awareness, Research, and Training in the Schools (HEARTS) Act of 2023 (Reps. Pallone and A. Kim)**

This legislation directs HHS to develop and distribute certain educational materials and resources regarding cardiomyopathy, automated external defibrillators, and cardiopulmonary resuscitation, to school administrators, educators, school health professionals, coaches, families, guardians, caregivers, State and local health departments, certain health professionals, and other relevant individuals. In addition, this legislation requires the Secretary to submit reports to Congress on the Centers for Disease Control and Prevention (CDC)'s national cardiomyopathy surveillance and research activities, as well as develop a risk assessment for individuals at risk of cardiomyopathy. This legislation also allows the NIH Director to expand and coordinate research with respect to cardiomyopathy and requires a report on NIH's ongoing research efforts.

**H.R. 7224, To amend the Public Health Service Act to reauthorize the Stop, Observe, Ask, and Respond to Health and Wellness Training Program (Reps. Cohen, Wagner, Cárdenas, and Carter)**

This legislation reauthorizes the Stop, Observe, and Respond (SOAR) to Health and Wellness training program through fiscal year 2029.

**H.R. 7300, Reauthorization of the Family-to-Family Health Information Centers (Reps. Sherrill and De La Cruz)**

This legislation reauthorizes the funding for family-to-family health information centers through fiscal year 2029.

**H.R. 7268, DeOndra Dixon INCLUDE Project Act of 2024 (Reps. McMorris Rodgers, DeGette, Cole, and Holmes Norton)**

This legislation authorizes the current INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE) Project at the NIH, which is currently funded to promote the scientific understanding of Down syndrome and co-occurring conditions and improve the quality of life of individuals with Down syndrome and their families. The legislation also requires reporting to Congress on the program's progress and related research.

**H.R. 5012, SHINE for Autumn Act of 2023 (Reps. Y. Kim, Castor, D. Joyce, and Kelly)**

This legislation would allow HHS to award grants for data collection and reporting related to still births and requires HHS to issue guidelines regarding proper training and processes for collection of data related to stillbirth, as well as disseminate educational materials. In addition, this legislation requires HHS to incorporate a perinatal pathology fellowship program or related program within an existing training program. This legislation also requires HHS to issue public educational guidelines and reports on the progress of the described programs.

### **H.R. 3916, SCREENS for Cancer Act of 2023 (Reps. Morelle and Fitzpatrick)**

This legislation reauthorizes the National Breast and Cervical Cancer Early Detection Program through fiscal year 2028 and makes certain modifications and updates to the program and reporting requirements.

### **H.R. 4534, Women and Lung Cancer Research and Preventive Services Act of 2023 (Reps. Boyle and Fitzpatrick)**

This legislation would require HHS to conduct an interagency review on the status of, and identify research and education opportunities related to, women with lung cancer. The review would include assessments of current research and access to prevention services, the availability of research opportunities regarding prevention, detection, and treatment, and recommendations for national public education and screening strategies.

### **IV. Staff Contacts**

If you have questions regarding this hearing, please contact Emma Schultheis of the Committee staff at 202-225-3641.